

**Written Testimony of
Robert Fiore
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Joint Committee on Public Health**

Senate Bill # 654, An Act Concerning the Availability of Prescribed Antiepileptic Drugs

My name is Robert A. Fiore. I am 53 years old, a resident of Milford and have Epilepsy. Being born in the 1950's, and growing up in the 60's and 70's, there was a stigma associated with Epilepsy. It was not spoken about. It was almost as though what people don't hear or see doesn't exist. It wasn't until the late 1990's that I actually felt "somewhat" comfortable to speak openly about it. However a few months before my temporal lobectomy surgery in January 2006, I made up my mind to become an advocate for epilepsy here in CT.

Many of the medications taken by people with Epilepsy are available in a generic form. It is dangerous for people with epilepsy to have their medication switched without their knowledge. The reason I am here today is to tell you about the experience I had when I switched to a generic version of Phenobarbital.

The cost of all my prescriptions, at one point in time cost over \$1,000 per month. This was the lowest possible expense despite using mail order services to order in bulk, where I was able to purchase 3 months supply of my medications for less what I would pay for 1 month at my local pharmacy.

Phenobarbital is in fact one of the lowest cost prescription drugs for Epilepsy, but I found that I was substituting cost savings for effectiveness and my general health.

In the summer of 2006, I started to use the medications purchased through a mail order service. Within a few days I started to have headaches. This could be seen as being usual, but after 5 straight days of headaches, I contacted my Neurologist. After speaking with him at his office, and talking through possible changes in lifestyle, he asked if I had changed my medication in any way. No – only where I had purchased the medication from. His response was to dispose of it, and refill the prescription at my usual pharmacy. This is what is causing the problems.

Although I was surprised with his response, I followed his instructions. Approximately 5 days later, I had absolutely no pain or headaches. This was almost 2 years ago. Ever since then I continue to purchase my Phenobarbital from the pharmacy that I have used for over 10 years with no issues or side-effects.

In conclusion I strongly urge you to pass this bill, which would require pharmacists to inform us and out physicians when switching medications from generic to generic. This will help not only myself, but can potentially help approximately 60,000 people here in CT who have Epilepsy.